Table 1

	M (SD)	Range
Percentage of prescribed doses taken	70.39 (21.47)	28.21 – 92.50
Percentage of days with correct number of doses taken	55.43 (23.11)	20.51 – 88.18
Percentage of days with partial adherence (1 - 99%)	26.75 (17.18)	8.18 – 56.82
Percentage of days with no prescribed doses taken	17.81 (22.59)	0 – 64.10
Length of medication interruptions (≥ 24 hours between doses), days	4.46 (7.45)	0 – 36

(e.g., increased conflict with caregivers) linked to decreased adherence. As such, it is important to understand adherence in this potentially at-risk group. This study is the first to describe patterns of adherence in adolescents who have undergone HSCT.

Method: Data for this study are from a larger project examining adherence in pediatric HSCT recipients. Participants included eight adolescents (ages 12-18) who had undergone HSCT and their caregivers. Participants used Medical Event Monitors (MEMS™), electronic pill bottles that report time-stamped indications of bottle openings to track adherence for the duration of the study (9 mo.), until all oral medications were discontinued (n = 2), or until the device was lost/no longer provided for download (n = 2), resulting in an average of 195.63 monitored days (SD = 119.87 days). Daily adherence was calculated by dividing the number of recorded MEMS™ openings per day by the number of prescribed doses for that day. The average length of medication interruptions (≥ 24 hours between doses) was calculated for participants prescribed daily medication (n = 7). Caregivers provided demographics. Clinical characteristics were obtained via chart review.

Results: Participants were primarily male (63%), Caucasian (75%), and non-Hispanic (75%). On average, participants were 14.07 years of age (SD = 1.41 years) and received their transplant at 14.00 years of age (SD = 1.41 years). Adherence data are presented in Table 1. Participant level data will also be presented.

Discussion: Overall, participants struggled to adhere to medication schedules, taking 70% of prescribed doses and demonstrating perfect adherence on fewer than four out of seven days per week. Adherence rates are similar to those observed in other pediatric populations and demonstrate the importance of routinely assessing adherence in adolescents who have undergone HSCT.

212

Ocular Chronic GVHD: Increasing Opportunities for Impact and Awareness

Ryan Ridges [1], Deborah Jacobs [2], Beth Beard [2]. [1] Boston Foundation for Sight; [2] Boston Foundation for Sight, Needham, MA

Introduction: Approximately 50% of HSCT recipients develop chronic GVHD and of these 60% suffer from moderate to severe ocular GVHD. The symptoms of ocular GVHD (OCGVHD), blurry vision, burning, foreign body sensation, pain, excessive tearing, and photophobia, have negative effects on quality of life (QOL). We attempt to identify opportunities to increase awareness, acceptance, access to treatment, and care coordination that can improve QOL in OCGVHD.

Methods: Retrospective review of 2 online surveys conducted by Boston Foundation for Sight (BFS) and keyword searches of BBMT and PubMed. Survey 1 in 2009 included

Table 1
NIH Consensus Project Ancillary Therapy and Supportive Care Recommendations for Eye GVHD and BFS Survey 1 Results

Therapy	Indication/Severity	N with GVHD who tried	Mod success	Sig success
Topical	Mild			
	Artificial Tears	44	45%	7%
	Viscous ointment/tears	NIS	N/A	N/A
Topical	Moderate/severe			
	Cyclosporine eye drops	35	8%	0%
	Topical steroid drops	28	29%	0%
	Lacriserts	10	10%	0%
Oral	Moderate/severe			
	Cevimeline	NIS	N/A	N/A
	Pilocarpine	NIS	N/A	N/A
	Doxycycline	26	23%	0%
Surgical	Moderate/severe			
	Punctual occlusion: plugs	36	16%	0%
	Punctual occlusion: cautery	20	20%	5%
	Partial tarsorrhaphy	5	40%	0%
Eyewear/ environmental	Moderate/severe			
	Occlusive eye wear	NIS	N/A	N/A
	Lid care/warm compress	NIS	N/A	N/A
	Bandage contact lens	6	33%	0%
Treatment not widely available	Moderate/ severe			
	Autologous serum eye drops	8	12.5%	12.5%
	Gas-permeable contact lens (Boston scleral lens prosthesis, www.bostonsight.org)*	41	17%	76%

NIS indicates, not in survey; N/A indicates, not applicable
* BostonSight PROSE treatment

1127 self-selected respondents from emails sent to 700 BFS patients and posts on 3 patient websites: Dry Eye Zone, NKCF and SJS Foundation. 51 reported OCGVHD (BFS patients N=41) and 476 dry eye without COGVHD (BFS patients N=147). Survey 2 in 2011 included 149 self-selected respondents from emails to 900 PROSE treatment patients seen in previous 5 years. 19 reported OCGVHD and 94 dry eye (also OCGVHD N=17).

Results: Survey 1 revealed 26% of COGVHD BFS patients first heard about PROSE treatment from an eye doctor, 26% BMT transplant team, 28% other medical doctors and 20% other sources; versus 46%, 0%, 1.5%, and 52.5% respectively for dry eye patients without COGVHD. Table 1 presents respondent reported experience and success with ancillary and supportive care recommendations for Eye GVHD from 2006 NIH consensus project. Survey 2 revealed 84% of OCGVHD reported PROSE devices daily wear. 79% would have pursued the treatment months or years earlier if possible, and 31% of these cited lack of awareness of PROSE treatment as a delaying factor. 11% consulted 6 or more ophthalmologists before finding PROSE; 11% 4 or more; and 28% 3 or more. Search of BBMT database on 6 combinations of the terms “ocular”, “chronic”, “graft versus host disease” and/or “GVHD” anywhere in title or body yields 12 citations including meeting abstracts. Search of PubMed using same keyword criteria for title only yields 22 citations.

Conclusions: Despite 2006 consensus workshop recommendations, including multi-disciplinary coordinated care by an ophthalmologist knowledgeable about HCT and GVHD, we have found that with OCGVHD receive higher level

treatment with demonstrated impact on QOL only on a delayed basis. BMT centers are more likely to be a source of referral than eye care providers. There is now increased availability of autologous serum, scleral lenses, and PROSE treatment. Increasing awareness among these BMT clinicians, eye care providers, and patients presents an opportunity for impact as far as improvement QOL for HSCT survivors.

213

Integrating Palliative/Supportive Care Concepts in the Blood and Marrow Transplant Setting

Pamela Rowland. Palliative and Supportive Care, Children's of Alabama, Birmingham, AL

The availability of Blood and Marrow Transplant (BMT) can provide hope and possibly life for patients with certain acute and chronic diseases that have no hope for cure. Unfortunately treatments that are necessary to achieve a cure can illicit untoward symptoms that seriously impact quality of life (QOL). While the goal of treatment may be cure, the challenge of treatment becomes managing the burden of those symptoms and maintaining a QOL that makes that cure worth the journey.

Symptom burden in the transplant setting presents a challenge to both the patient and the medical team. High dose chemotherapies with high emetogenic potential can illicit severe nausea and vomiting both acute and delayed. Some acute complications of transplant include mucositis, anorexia, pain, graft versus host disease and immunosuppression. Acute symptoms can become chronic. To address symptom burden it seems logical that the experts in each of these disciplines, BMT and palliative/ supportive medicine, should partner to give these patients the best possible outcome.

Obstacles to excellent palliative/supportive care in the BMT setting can occur when consults are based on clinician values, rather than patient needs. Many clinicians mistakenly believe palliative/supportive care translates to end of life care. The World Health Organization reports palliative/ supportive care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The intent of this paper is to outline a proposal for the integration of palliative/supportive care concepts in the BMT setting that can facilitate the transformation of the latest knowledge into strategies that help to manage the burden of symptoms in the BMT setting.

214

Body Mass Index as an Indicator of Prognosis in Patients Undergoing Allogeneic Hematopoietic Stem Cell Transplantation: A Single Institution Experience

Guillermo Jose Ruiz-Delgado, Julia A. Lutz-Presno, Carlos Alarcon-Urdaneta, Guillermo J. Ruiz-Arguelles. Centro de Hematologia y Medicina Interna, Clinica Ruiz, Puebla, Mexico

Both obesity and malnutrition are considered risk factors for complications and increased relapse and nonrelapse mortality in hematopoietic stem cell transplantation (HSCT). An inferior outcome after allogeneic HSCT has been reported in obese adult patients in both allogeneic and autologous HSCT: Overweight individuals seem to develop more complications of graft *versus* host disease and more infections than its normal counterparts. Between March 1996 and December 2010, a total of 138 patients received an allogeneic HSCT in the Centro de Hematología y Medicina Interna of the Clinica Ruiz. Patients were stratified according to pretransplantation body mass index (BMI) values: 17 patients had low BMI, 62 had normal BMI and 59 patients had high BMI. Median overall survival (OS) for these three groups were respectively 9, 12 and 22 months. Patients with a low BMI had a lower OS than those with a normal BMI (58-month OS of 24% versus 32%), whereas patients with an increased BMI had a better outcome (median OS of 22 months and 43% OS at 130 months) than those with a normal BMI. Our findings demonstrate a correlation between pretransplantation BMI and posttransplantation survival and should provide insight into how to better manage nutritional support for patients undergoing HSCT.

215

Factors Impacting Family Decisions to Pursue Transplantation for Children with Sickle Cell Disease

Amanda L. Thompson [1], Eileen Twohy [1], Jackie Dioguardi [1], Emily Riehm Meier [2]. [1] Children's National Medical Center, Washington, DC; [2] Division of Hematology, Children's National Medical Center, Washington, DC

Background: The only cure currently available for sickle cell disease (SCD) is hematopeotic stem cell transplantation (HSCT). Barriers preventing widespread application of HSCT include limited donor pools and lack of family education about HSCT. To our knowledge, no studies have examined medical and psychosocial factors that influence families' decisions about whether or not to pursue HSCT for their child with SCD.

Methods: Surveys created by members of the Sickle Cell, Blood and Marrow Transplantation, and Psychosocial teams were distributed to family members attending an education symposium about HSCT for SCD at a large metropolitan hospital. Surveys were anonymous, optional, and approved by the Institutional Review Board; participants were entered into a gift card drawing. On a scale from 0 ("not important at all") to 3 ("very important"), participants rated the relative importance of 17 factors that may impact the decision to pursue HSCT.

Results: Thirty-four attendees completed surveys; 15% were parents/guardians of patients who had already had a transplant (n = 5), 73% were parents/guardians of patients who had not had a transplant (n = 25), and 12% were "other" family members (n = 4; e.g., aunt, grandmother). Items that were consistently rated important (i.e., >80% of respondents rated them "somewhat important," "important," or "very important") represented multiple domains, including: HSCT-related risks (e.g., death, infertility, transplant failure, GVHD), prevention of SCD complications, medical team interactions (e.g., hematologist recommendation, trust in medical team), and psychosocial concerns (e.g., emotional strain on patient/ parents, social support). Items not consistently rated important included financial strain, impact on sibling donor, child losing hair, child missing school, and religious beliefs. Mean importance ratings were highest for risk of death (M = 2.91) and prevention of SCD complications (M = 2.82) and lowest for religious beliefs (M = .68) and child losing hair (M = 1.00). See for importance ratings of individual survey items. There were few differences between ratings of family members who had been through transplant and those who had not.

Conclusions: When considering HSCT for SCD, parents and caregivers report HSCT-related risks, interactions with